1. **TITLE: Transition- the experiences of support workers caring for people with learning disabilities towards the end of life.**

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4. **People with learning disabilities; adults; end of life care; support workers; paid carers**

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Abstract:

Aim: This research aims to provide a better understanding of the experience of support workers, as paid carers, caring for adults with learning disabilities nearing the end of life in residential settings.

Background

In the last 100 years, people with learning disabilities (also referred as 'learning difficulty', 'mental retardation' and 'intellectual disability' internationally) are living longer with life expectancy approaching the population norm and more likely to die from diseases such as cancer, respiratory and vascular diseases. Service based accommodation has become the foremost provider for people with learning disabilities in their late 30s or over in the UK. In the midst of the transition from living to dying, and even afterwards, the needs of support workers are often neglected against a background where most are unqualified, often with little experience of death and dying, with limited access to clinical supervision and education.

Methods

Three focus groups involving 13 support workers were conducted at three Independent service provider settings for people with learning disabilities in London.

Findings

In recounting the experiences of these groups of support workers, six themes are described: strong emotional bond and identification; collaboration with other

services; training issues around the extended role; support within the organization; relationship with family/other residents and filling the ‘void’.

Conclusion

Although support workers play a key role in meeting the end of life care needs of people with learning disabilities in residential settings, their own needs are often neglected. There are still significant gaps in understanding these needs and practice development in this area

Key words: people with learning difficulties; adults; end of life care; support workers; paid carers

Background

Learning disability is ‘a state of arrested or incomplete development of the mind, which includes significant impairment of intelligence and social functioning’ (1). It is also described as ‘a reduced ability to understand new or complex information, to learn new skills (impaired intelligence) and to cope independently (impaired social functioning), which began before adulthood and which has a lasting effect on development’ (2). It is estimated that in England there are 1,198.000 people with learning disabilities and that by 2021, the number of people with learning disabilities over the age of 50 years is expected to rise by 53% with life expectancy now approximating the population norm (3). While younger people may die from congenital abnormalities or infections, cancer, respiratory and vascular diseases are the most common causes of death for older disabled adults, conditions of typical concern to palliative care services. As people with learning disabilities live longer, they will enter the dying phase of their lives in some form of learning disability service setting, requiring these services to be better prepared for the transition to end of life care (4)(5).

The evidence has continued to suggest that some groups in society are still excluded from the best of these services and continue to experience ‘disadvantaged’ dying (6) (7). People with learning disabilities have been identified as one of the most vulnerable and socially excluded groups in society, with their healthcare needs often unmet, particularly in relation to cancer care (8) (9) (10). The Disability Rights Commission and The Healthcare Commission have called for sweeping and sustained changes to services for people with learning disabilities (11)(12). In 2008, the Independent Inquiry into Access to

Health care for people with learning disabilities in the UK reported that the health care system contributed to their vulnerability, resulting in undue suffering and a higher likelihood of avoidable deaths (13). More recently, the Confidential Inquiry into Premature Deaths of People with Learning Disabilities (COPOLD) highlighted the continuing need to identify people with learning disabilities in healthcare settings and to ensure the provision of 'reasonable adjustments' to avoid their serious disadvantage (14). On a more positive note, the document 'Widening access to palliative care for people with learning disabilities (2013) praises the inclusion of the specific needs of people with learning disabilities in an equality impact assessment within the English National End of Life Strategy and the progress made by organisations such as the Palliative Care for People with Learning Disabilities Network- www.pcpld.org (15). However the author still describes much of the response of palliative care services to date as being inequitable with a seductive emphasis on giving 'equal' service.

Health care professionals generally lack awareness of the emotional or educational needs of learning disability support staff when their service users have a terminal diagnosis. A UK survey revealed that one third of specialist palliative care professionals had never supported a person with learning disabilities in palliative care, even though it could be expected that 1 in 40 of palliative care patients should have a learning disability. The survey also identified delayed diagnosis, difficulties in assessment and control of symptoms, consent processes, communication and family dynamics as challenges in meeting the palliative care needs of people with learning disabilities and cancer (16).

Despite a steady increase in published materials since 2000, research data around the palliative care needs of people with learning disabilities remains scarce. Subsequent position papers in other countries highlight this paucity of information, as well as the gaps in service provision and research evidence (17) (18) (19). In England one of the key barriers to people with learning disabilities accessing palliative care is the lack of understanding and training of the staff working with them (20). Learning disability staff are often young, lacking in training and experience, staffing levels are low and turnover is high. Previous studies have highlighted the impact of providing such care. In 2004 a retrospective study by Todd explored the way in which services organised care for 17 individuals with learning disabilities who had died in supported living settings. Staff reported that they did not feel they were prepared for such endings, felt more and more drawn into a process of 'contested dying' where as the care became more complex, they were pulled in several directions leading to feelings of unpreparedness and being overwhelmed at times (4). In another study by the Mental Health Foundation interviewing the carers of 21 deceased people with learning disabilities, a key variable around place of death was whether staff could 'stay the course', had access to other services as well as help with dealing with their personal and professional feelings as important means to support their enhanced role (8). A study by Ryan et al in Ireland interviewed 64 individuals from intellectual disability services about their experiences of end of life care for people with intellectual disabilities and many felt underprepared to meet the need and this led to staff stress (21).

This study aimed to solely research support staffs' experience of caring for people with a learning disability at the end of life, identify their own needs as

well as factors that influence their ability to provide end of life care and impact on the quality of end of life care for people with learning disabilities.

Methods

Study design

A qualitative design utilizing a focus group methodology was selected as the most appropriate method to generate new knowledge in a previously unexplored population with no prior data. The focus group method is a technique of group interview that generates data through the opinions expressed by participants. Focus groups have become an increasingly popular method of data collection in health care research. They can produce a lot of information quickly and people usually feel comfortable in a well led focus group discussion. However, there are challenges as the researcher has less control over the flow of the discussion and the results can be harder to analyze (22). As gaining access to support workers was challenging, it was felt a focus group methodology would be more convenient.

Consultation and ethics

The author consulted widely with key stakeholders including the Palliative Care for People with Learning Disabilities Network (PCPLD), a group of practitioners from disability or palliative care services that also has people with learning difficulties and their carers as members, as well as with the local learning disability team where the study was conducted. Ethical approval for the study was obtained from the King's College Research Ethics Committee (**CREC/07/08-49)**.

Recruitment

Three focus groups were conducted consisting of residential support workers who had direct experience of caring for a person with a learning disability towards the end of life. Participants were required to have cared for a service user who had died at least three months previously. Interviews were conducted at three different service provider settings in central London. The managers of local care provision organisations were initially approached by a member of the local learning disability care team who passed on a letter of inquiry with an information pack. Upon approval, each manager was asked to discuss the contents of the letter with their teams, informing them of the nature and importance of the study. This was followed up by a phone call from the researcher to confirm participation or not.

Data collection

Each participant was asked to provide demographic information: age, sex, ethnicity, educational background, personal experience of disability, learning disability work experience, opportunities for in-service training, access to support, understanding and experience of palliative care. The interview guide addressed their previous experience of death and dying among service users, practices of disclosure in death and dying, relationship with others involved in client care, place of care and post death needs and support. Interviews were recorded and transcribed verbatim. In order to encourage participants to generate recommendations for better end of life care, a final single scenario was presented; “Sheila is a person with learning disabilities you care for. She

is very ill. She is not going to get better. What kind of support do you think you will need to be able to look after her as she nears the end of her life?

Analysis

Demographic data were tabulated using descriptive analysis. The focus group data were recorded and transcribed verbatim. All identifiers were removed. The following steps were employed for all the data analysis. In order to ensure rigor and reliability, each focus group transcript were reviewed independently by the researcher and a colleague who was experienced in palliative care research. This was meant to address a common concern about the reporting of qualitative data that anecdotes supporting the researcher's argument have been selected, or that undue attention has been given to rare events emerging from the data. Firstly, all the transcripts were read through to obtain a sense of the whole data and develop themes. Secondly, the responses were re-read line by line to identify significant text segments, using the participants' words as much as possible, and to develop preliminary themes. The final themes were compared to avoid any obvious overlapping. In order to maximise face validity, the transcripts were also posted to all three teams to check for accuracy. No corrections had to be made although this process stopped short of member checking.

Summary of Main Results

Six core themes were identified. These were 1) strong emotional bond and identification, 2) collaboration with other services, 3) training around the extended role, 4) support within own organization (including resources), 5)

relationship with family/other residents, 6) ‘filling the void’ and coming to terms with the loss. Exemplary quotes are given for each theme in Supplementary Table 2, with the anonymous participant ID shown for each quote to demonstrate reporting from the breadth of the sample.

1. Strong Emotional Bond and Identification

The strong emotional bond and identification that exists between support workers and their residents was demonstrated across all groups. Respondents struggled at times to maintain the boundaries between their personal and professional relationship with the resident, which often reflected the length of time they had worked with the resident, in some cases more than 10 years (Quote 1a). Although staff referred to residents using professional terminology such as ‘service user’, in some cases, it was clear that they were very deeply attached to the person that they cared for (Quote 1b).

2. ***Level of collaboration from other services***

The experiences of the carers was largely positive regarding collaboration with other services and where the person died at home, this was acknowledged as a key factor in supporting staff. (quote 2a). However, there appeared to be evidence of denial and a lack of preparedness for seeing residents entering the dying phase of their lives, which meant that, one of the homes with a resident in the advanced stages of dementia, was slow to engage with palliative care services despite a clear picture of gradual deterioration over months (quote 2b).

3. Training issues around extended role

The data corroborated the broad feeling among support workers that they needed access to extra training and support when caring for a resident near the end of life. This was heightened in a workplace setting where it was standard practice for support workers to be on their own with residents, even when they were dying. (quotes 3a and 3b).

4. Support within own organization (including resources)

Another critical factor for staff was the level of support that the teams had from their own organisations. For one of the teams, this was an ongoing battle (quote4a) whereas both other teams felt very supported by their management translating into extra staff at night, increased individual support and affirmation (quote 4b).Ironically, the appreciation from senior management created a paradoxical fear among staff that the home would develop a reputation for end of life care in learning disability circles, prompting increased referrals of that nature (quote 4c). Again, the lack of a specific organizational policy or guideline or formulated plan on caring for residents who have a terminal illness was seen as a way of denying death (quote 4d).

5 Relationships with family/other residents

Support workers evaluated relationships with individual families in both a positive and negative light, but were convinced of the importance of collaboration. However, they did highlight incidences where their relationships with family/other residents led to a shift in responsibility to caring for the resident's parent (quote 5a), and to the resident's friendships within the residential setting (quote 5b).

6. Filling the void- coming to term with the loss of a resident.

Staff in all three focus groups raised the difficulty of coming to terms with the loss of a resident, the necessity of filling the resident's space after they had died (quote 6a) and the importance of the organisation taking a sensitive approach. Even where a long time had elapsed since a resident had died, staff still expressed strong feelings of attachment (Quote 6b).

Recommendations for better support: scenario responses

The three focus groups made recommendations for better end of life care that centred on organizational support (quotes R1-3), and service development including earlier involvement from the specialist palliative care team (quotes R4 and R5).

Discussion

This study builds on previous studies acknowledging the important role that learning disability staff have in providing quality end of life care for their service users (4) (8) (15) (21). These studies have pointed out previous efforts to explore the educational and training needs of learning disability staff concerning end of life care while at the same time providing further insight into the emotional and psychosocial effects of providing such care. The findings in this study also identified the strong emotional bond and identification that the support workers felt towards the residents they cared for and how this appeared to strongly influence the care they wished to provide, becoming a blue print for supporting the person. It also raised the potential for staff to use their own human responses over any formal training to respond to people in distress and

highlighted a concern for their emotional well-being when providing end of life care in the absence of more formal support systems. There was an absence of a supervisory relationship or a reflective space where support workers could process emotional difficulties, especially as it was standard practice for staff to be managed and supervised by the same line manager. The Ryan et al study corroborated this study's findings in a number of areas, for example, that health and social care professionals experienced disenfranchised grief following the deaths of service users when their loss and grief was not acknowledged and their reluctance to avail of formal support offered by their colleagues. Collaboration between family members and staff was also evaluated in both a positive and a negative light, where a difficulty in the relationship appeared to consistently heighten the emotional distress of staff caring for service users at the end of life. Participants in this study were also broadly positive about the importance of collaboration between services. At the same time with long periods lapsing between cases, there were challenges to sustaining those relationships including the potential for significant clashes of professional interests and organisational culture.

While the development of training and information for learning disability services has received increasing attention, and this has resulted in the development of some resources, it is not clear how much support staff are enabled to use them. Despite commitment to keep terminally ill clients in their own environment for as long as possible, even where there was overwhelming support from two of the organizations, this failed to translate into policies and procedures. Organisational responses that could address common issues

include a shared philosophy towards end of life care, training needs, disclosure of diagnosis, advanced planning, dealing with family/relatives, access to different services, extra resources available, support for staff, as well as a meaningful person-centred plan. Good practice examples are rare and key factors identified were attentiveness to the person's needs, a commitment by all staff to provide person-centered care, and collaboration between healthcare staff, learning disability staff and family (23) (24) (25).

Where support workers take on a 'de facto' family role, there is a strong argument for bereavement support, particularly for those who have known a resident for a lengthy period. This study also supports the proposal that some form of ritual of remembrance is important for both staff and residents when a resident dies and the importance of the organisation taking a sensitive approach to workers' needs. Reporting from their experience of implementing a project aimed at increasing access to palliative care for people with learning disabilities through strengthening relationships between learning disability and palliative care services, Cross et al concluded that any effective change in care has to be embedded change, i.e. tackling both culture (how people think) and structure (how things are organised) (20).

Strengths and Limitations

The voices of support workers are currently under reported in palliative care literature. This study focuses solely on their experiences of providing end of life care for people with learning disabilities and adds knowledge in this area. It also seeks to identify factors that affect support workers ability to 'stay the course' which has implications for clinical practice in this area.

The study also has a number of limitations. The principle researcher was involved clinically with one group of support workers so a potential for contamination could not be avoided. This highlights again the difficult challenge of recruitment into palliative care research, even when the use of staff and lay carers is thought to reduce this (26). Recruitment was via access through the local learning disability team. This is likely have introduced an element of bias in the study as stable services which were thought to have delivered a good quality of care may have been more likely to be referred to the study. Although the transcripts were posted to participants for comments, the research data analysis stopped short of any further informant feedback to help improve the accuracy, validity and transferability of the study.

Implications for clinical practice

Although support workers play a key role in providing end of life care for people with learning disabilities in residential settings, their own needs are often neglected. There is enough evidence now to suggest that there are still significant gaps in supporting learning disability staff in providing end of life care. This points to an urgent need to develop strategies that will guide learning disability organizations to start formulating policies and procedures that address some of the issues already identified in this study, such as: extra resources for training; staffing; corroborating with other services; bereavement leave; more time for regular meetings; sensitive approaches to difficult issues such as disclosure, marking the loss of a resident and filling the space left

behind. These policies and procedures are critical for preparing and equipping learning disability staff to provide palliative care.

There is a challenge as well for palliative care organisations to look at more robust ways of improving their partnership with learning disability services in order to improve the quality of death and dying for people with learning disabilities nearing the end of life. Several UK hospices have developed education programmes for care staff. For example, Dorothy House Hospice in Bradford on Avon (UK) has a series of rolling programmes for nursing and residential home care workers which are co-facilitated by hospice educators, learning disability professionals and service users. Another possibility is the development of 'link workers' who can improve care outcomes and maintain the partnership between both services.

Case reports are still the most prevalent method of exploring difficulties and evaluating best practice in palliative care and learning disabilities. Whilst direct interviewing and focus groups might elicit useful data, studies using direct observation may be more appropriate in the future.

Conclusion

Adults with learning disabilities are now enjoying a lifespan similar to the norm for the general population that has heralded a new transition from living to dying for people with learning disabilities. Although people with learning difficulties can access mainstream palliative care services, the reality is that access to such a service does not necessarily imply benefit. One of the key barriers to people with learning disabilities accessing palliative care is the lack of understanding and training of the staff working with them. A key variable around

preferred place of death is whether support staff can ‘stay the course’. Just as importantly, for any kind of change in care to be embedded, both cultural and structural issues have to be addressed by learning disability service providers. Greater effort is also needed by palliative care services to build on the highly valued partnerships with outside agencies that need to have greater expertise in supporting both people with learning disability and their support workers. As services that are often proactive in developing new responses, hospices and palliative care services are well placed to lead this process.

Sample characteristics

The sample characteristics are described in Table 1 below.

Table 1 Sample characteristics (n=13)

Gender	Male n=1 Female n=12

Age	60+ n=1 50-59 n=1 40-49 n=6 30-39 n=3 20-29 n=2
Education (National Vocational Qualification level)	2nd level n=6 3rd level n=7
Ethnicity	White Irish n=1 White British n=5 White (any other) n=2 Black African n=4 Black Caribbean n=1
Years working in learning disability	<1 year n=0 1-5 years n=4 6-10 years n=4 11-15 years n=0 16> years n=5

Supplementary Table 2

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